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Episode name: How stories shaped every aspect of our mixed methods study

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Transcript

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Thanks for having me. Yeah. So weird to be up here, not there. But no, it's lovely to be. I really enjoyed the course and I loved my Masters in general here. So yeah, thanks for inviting me back. And Marie was my supervisor as well, so. Yeah. Today I'm gonna. Be about #1. How I qualitative study that was done fairly small qualitative study actually had a large. Impact on a bigger mixed method study and carries on and I'm going to do it through the lens of our study, which I'll explain. I get this to work. Not working. Is that true?

You know.

Yeah. Don't mind if it doesn't work. Ashley going. It's OK like that? Yeah, very good.

Yeah.

I just wanted to say that I'm part of such a bigger team than me and the qualitative study that I'm going to be talking about wasn't actually led by me. It was led by my current supervisor, Professor Michelle Hayes. Big team of collaborators funded by Barts Charity and then I went on to lead the sort of mixed method study later on with many of the same collaborators plus a few supervisors and and really importantly a very strong PPI group of we call them parent partners and they're part of the research. Too, and and I'm funded by HARP, which is a little bit like an NIH fellowship in that it stands for health advances for underrepresented populations and basically unfunded for three years as though I've been working as an occupational therapist to do a PhD in the topic that I presented. So. And that's sort of the wider team and very much. Yeah, we're speaking about the study. It's not not necessarily my study but but the wider team study too. So I don't know how many of you are familiar with the population around children with complex neuro disability or cerebral palsy. So I'll just introduce you to that briefly before speaking about the qualitative. That was done. Then I'll speak about how that influenced the current mixed method study and sort of how these stories continue to influence the future studies that might come. Yeah, when I speak about stories. I do speak about the sort of the qualitative work that was done and the power of the stories. That were told in. Those, but also to remember that it was done in quite a systematic way as well in a study, but we also use stories from our PPI groups and from observations. So really gathering stories from all over the place has. Has been very powerful in a lot. Of this work. Anne Marie did introduce me already as an OT. I studied and qualified in South Africa and I've worked. Sort. Of both in. South Africa and the UK in private and

government state. Things pretty much always with children, and I've always had an interest in supporting the families and the parents of children with complex disabilities. I found this photo on a website of when I newly graduated and I was working in a very rural hospital in South Africa and there was a charity that trained carers to support. Of the carers of children with disabilities, with called the career to care programme and that really started my research career and my interests. But it was funny to find myself still on the website there. But that's sort of the the work in South Africa a long time ago now. When I was in the UK, I did my masters here and I did a which you probably know now a small qualitative study and looking at a charity in the UK that also ran groups for families of children with complex, you know, disability. And I looked at the impact on maternal well-being. To kind of hear the the threads go my PhD application then was about a programme that was developed in Uganda, also supporting families of children with disabilities, and we're adapting in pilot testing. Yet for the UK and the NHS. And clinically, I'm based in Newham, east London. I don't know how many of you know much about Newham or that area. Tower Hamlets in east London, but it's an incredibly diverse area, but it's also got high levels of deprivation. So sort of one in two children are considered to be living in poverty. It's also got the most languages. And any bar spoken in the whole of the UK. So it's quite an interesting place as well to think about this kind of study and as well. I also advocate for OT's and other allied health professionals in research because we are very underrepresented in the research world. So complex neuro disability. The reason I don't just say cerebral palsy is because actually there are a lot of other conditions which look similar and and might not meet. That criteria so. But what I'm. Referring to is a long term health condition which was either acquired at birth or later on and resulting in functional difficulties, so functional difficulties. The things that children want to do every day, whether it be, get up and get dressed, go to school, play. These are impacted due to an impairment in the brain or neuromuscular system. And in CPX, sort of 2.1 in every 1000 live births, but in high income countries, it's about 1.6 and in lower middle income countries, it's over three. So there really is a higher rate and low middle income countries, but fairly common as well, yeah. So these children might have physical difficulties, but they also might have sensory difficulties, communication difficulties, difficulties with eating and drink. Thing and they really require a host of different services. You've got orthotics over there. This looks like maybe an OT session or a physiotherapy session. And actually someone is required to actually deal with all of these different needs and appointments and. And that is often the parent or the caregiver. So this has been extremely widely researched. That parents of children with disabilities present with poorer health outcomes, so this can be physical health, mental health, emotional well-being, social support and and just numerous qualitative and quantitative studies have been done. I generally will just flick through some of them over. And but it has been researched over and over and over again. Stress quality of life, mental health. And we've kind of got to the point, it's like, what are we going to do about it? It's been really well researched, but we need to think about what comes next and. And so this is where we start thinking about where the work begins and then NHS clinician who happens to be also my supervisor, Professor Shai is, she's a paediatrician and she was sort of. Diagnosing children in the clinic and sort of sending parents on their way and really seeing this gap and that parents really needed support. They needed more information about what the diagnosis was. They needed to be put in touch with other parents and and she sort of felt like they were just dropping off a Cliff. After

that, she spoke to people and appointments and thought what they could do. And actually conducted a literature review to find out what was being done in the rest of the world to think about what could be done in Newham and East London, where she was working. And through this literature review, they found the Ubuntu programme and Ubuntu was previously called getting to know cerebral palsy. And it's a caregiver group programme delivered by caregivers and healthcare professionals that supports other caregivers in the community and works through different topics about how to care for your child. So not only does it teach them skills and knowledge, but it also provides opportunities for social support, and they also discuss topics like Stigma and how to navigate the community when you have a disabled child. I'm really. Using this literature review and looking at all sort of programmes all over the world, even in low middle income countries, we found quite a low cost programme Ubuntu that we're gonna try to sort of pilot in, in the NHS and that's often referred to as something called reverse innovation. But that's a little bit problematic in itself the term. Because it seems innovation is 1 directional from high income countries to low income countries. But we do like to think about the decolonisation of healthcare innovations now and as sort of going against the colonial perspective, that research and work is done in high income countries and then presented in low income countries. So this is kind of turning it up. It's on its head a little bit and thinking about what ideas can we get from low resource settings. Thinking about the NHS. As a resource constraint setting at times, especially now nowadays where we're facing this workforce crisis and budget cuts and everything like that, thinking about programmes that do cost less. So that's sort of an example. Of. Decolonized health innovation. But if I speak a. Little bit more about Ubuntu. The original programme was called Ubuntu, developed in Ghana. It was then adapted to be called Juntas in Brazil and Colombia to work with children with congenital Zika syndrome, where the Zika virus was going around. Similar programmes. Similar groups was in. Adapted for Uganda and it was called baby of Umm 2 and that was just for children, nought to three who were at risk of these diagnoses. Also very similar groups similar programme. And finally, it's also been adapted in Uganda as well, called Ubuntu Balamu, which is a programme based in in schools, and it's about encouraging inclusive education and understanding of disability. But what the team actually thought would be really appropriate for new in for East London was maybe Ubuntu and this was because it was those younger children who'd just been diagnosed. So it's a community based programme. It's participatory, so it means that when they're in the group, it's not just teaching sort of lecturing the group about different topics. It's very much parents problem solving together and discussing the topics. It's facilitated by someone with lived experience as well as a healthcare professional. And as you can see, there's different modules, so positioning and carrying children learning to move, learning to communicate, but then it's also got topics around togetherness and belonging in the community and thinking about access in the wider community. All right, so. The idea could have been. This is a great programme. Shall we just go? Let's adapt. Let's pilot test and let's go for it. But the team didn't actually do that. What they did is they stood back a second and. Planned a qualitative study. And I do think this is interesting because there. Is there is sort of a? A. A willingness to just want. To go out and try. But the fact that they stepped back applied for a bit of funding through Barts charity and decided to do a qualitative study has made such a huge difference in this wider sort of adaptation mixed method study, which I'll explain, and that's what I'm really talking about today. So

the qualitative study, why did they do it? And maybe a reason could be to explore the context. What you've got is you've got, as I said, this really interesting, this diverse area of London to think about what those local needs are and that can be really done in a qualitative study to test the concept of the programme with the people working and living in those. Areas so it doesn't have to be doing it first and then testing it. You can also bring the idea to the people and get ideas before you just get going. And 3rd to receive recommendations for the potential adaptation of the programme. So if you feel that there's sort of a warm response through your participants thinking about what recommendations they would have for adapting the programme, and this was all sort of reasons why they conducted their quality study in the beginning, they called it encompass because. Encompass in the in the dictionary sort of means to include comprehensively, and it's got sort of a warm feeling around it to encompass, to hold, to nurture. But it's also got the word compass in it because it thinks about navigation as well. And navigating the journey of being a parent and a child with the disability, but also navigating the services. What they need to do the wider community. So that's why the programme and the study was called Encompass and the aim of the qualitative study was to explore the concept of this Ubuntu programme amongst caregivers and healthcare professionals in East London. So this is West Highland Health Centre, where I work on a Monday and that's in Durham. And that's where the paediatricians and therapists are based. It's a child development centre. So to explore what they thought, those who were working there and those who are accessing services there about their volunteer programme. And the team recruited 18 participants and they had six healthcare professionals from different backgrounds and 12 parents, carers of children with complex near disability. They were mostly cerebral palsy, but but others were not, and what they did is they did two rounds of semi structured interviews. So the first round they asked. If they thought the Ubuntu programme might be feasible and how they felt it would be accepted in the community, so it was around feasibility and. The second round of interviews focused on the potential for adaptation. So what the team did was they gave a PowerPoint presentation of each module and then asked the participant to feedback. What would you change? What would you add? What would you take out, and would you include any other modules? So there was, as you can imagine. A real depth. Of qualitative data that was collected between these two rounds of of semi structured interviews. And because there was so much data, there were different ways it was analysed. So in terms of the first kind of aim of the project was gaining insights about caregivers experiences, but also their priorities and what they felt was needed in the community. And this identified service gaps and. This was analysed inductively using an inductive thematic approach, so that's when you have your. I know you've learned this. All this week but. When you've got your codes, you group them into categories and then into themes and so this worked really well for an inductive thematic approach because we were really interested in the data and what the experiences were. And and what they felt the gaps in the healthcare service was. The other data around the acceptability and the feasibility of the programme, what the potential barriers and enablers were, were analysed differently, so they were analysed inductively first, so codes were created, but then they were also put into theoretical frameworks. So that was deductively. Then. If this is making sense with what you've been teaching this week. But they they put them into these two frameworks. The theoretical domains framework and the theoretical framework of access of acceptability, and and they were then able

to get barriers and facilitators of what they thought the participants. Of what the participants thought would be for their bounty programme to be implemented in their setting. And then finally there was. A lot of data around. What the recommendations would be for adaptation, and this was very much analysed, I've said descriptively because we sort of just grouped together what the recommendations were and brought that into the adaptation stage in the next method study. OK, so I've described the methods I'm going to briefly talk about the results, but then I will go into how it influenced everything. Else. So remember the first set of methods I. Said were coded. Inductively. That the results were. Coded inductively and we looked at the sort of. Themes that that. Emerged or that were developed based on the priorities of those who care for children, the complex neuro disability. So the first theme that developed was the caregiver mental health was extremely important and this should be looked at by healthcare profession. Girls and and there were multiple courts around us as well. This is not. New to us but. It further confirmed that this is something we should. Be looking at. The second theme was around the information gap and this really relates to when parents go into a paediatrician appointment, get the diagnosis, they really feel like they need some more information, that's not jargon. Britain and that's able to be understood quite easily. And this is often sometimes useful for parents to connect with other parents and hear sort of information from each other that that they're able to sort of understand that they've said it feels a bit more real. Sometimes. Yeah, and difficult to understand as of you see in the court there. And then the third theme was around the need for holistic support and this sort of speaks the disjointedness of services, which I think you probably see in many different parts of the NHS. But this is a very powerful court and it speaks about a mother who walked in. Do an appointment. Yeah, she had a boy with her and she served because she had no idea that the diagnosis was. Coming. There was. Nothing this child's got. Cerebral palsy. Not even a telephone number or a support group. Just absolute darkness and that kind of encompassed the. The idea that there really. Was a lack of support for these parents. As I said, these results were expected. They support previous evidence, but they really also highlighted the implementation gap. As I said, we've got a wealth of research that shows caregivers needs of more support. They're struggling with their health. But there is also this implementation gap of what are we doing about it and how are we supporting them? But it also gave context to the future work. So what it did is it looked at parents, cares in our local context. As I said in. London and potentially, you know, future services or future programmes could look at this these results and think or maybe our maybe our borrowers maybe our situations might be similar might be an urban borough, it might be high lives for diversity in terms of culture, language, ethnicity and and really think about this. So we've just written a paper about the. These results actually and think about this paper in terms of our setting too.

Yeah.

So those are the 1st results about caregiver experiences. The 2nd results were about the acceptability and the feasibility that they thought about their blood 212 programme and participants thought that there might be potential benefits to the bridging programme about improving parent well-being, pulling this information gap, like I said. And meeting a local need. They spoke about there being lots of support for children's autism and similar diagnosis. Obviously not enough, but a lot of emphasis on that and not so much on children with cerebral palsy. But they all spoke about potential barriers, so thinking

about language, the differences in children, so the differences in severity of diagnosis and also funding as a barrier. And this is really important because when you get to sort of the adaptation phase and the piloting phase, there are going to be key uncertainties that you can have to face. But having this, these qualitative results. In the beginning about potential barriers makes you start to think about that already, and it gets you into planning. And the third set of results I said were about the recommendations for adaptations, and I won't go through them all because I've just got lists and lists and lists. Of them here but. It's really thinking about the different different modules, the timing of the groups, how to how to conduct the groups, who should facilitate, how they should facilitate. And we just had, yeah, extremely rich data on all of these things. So that's a qualitative study. And. And what I'm going to? Do now is talk about how the. Qualitative study influenced my current mixed method study, which is what I'm doing in my PhD. And I sort of. Separated this into five different ways and the first was about funding. The second was the methods for the mixed methods study. The third is about key decisions around implementation. The 4th is creating the adapted manual and the 5th is more fun because it really has supported with that. So as I said, I in my PhD, now I'm currently adapted or we have adapted the programme and we are pilot testing it now in the community. But in order to do that, I had to get funding. So what I was able to do is when I applied for the PhD and I applied for the fellowship, I was able to give the preliminary results of the qualitative work. So I wasn't coming in saying, well, clinicians are saying this. I think it's a really good idea. You know, research says we should do this. I had quite concrete. Evidence of the local need in that particular borough from the qualitative study, but also evidence of the exact implementation gap, but also evidence about what they already thought about the new programme. So there was so much data already to bring to my PhD application and into the Internet. Use and and I think that is really why I got it because there was all of this data already and it seemed almost like, well, this is obviously the next step for you to go on and work on on what's been done already. It also helped to for my. Patient and public. Involvement group and speaking about stories and the power of stories. A lot of the quotes that were taken from the first quantitative study. I kind of used to talk to parents who might be interested in becoming research partners with me to speak about what other parents have already said in the community. And I think this did really speak to future parents who would be involved in the research because it was real and the stories were real. It wasn't necessarily. Yeah, every like. A A complex medical sort of research paper that I was presenting. I was presenting stories from people who were in the same bar as them in very similar situations. And through that, we have formed a really strong group of parents who are now very involved in the research and have kind of been involved in every step of the mixed method study. Yeah. So that that helped. And then also. We sort of were able to publish more about these rich insights that I said about the local context, about the caregiver stories. It wasn't necessarily the plan in the beginning, but having these can be very helpful. As I said, for similar context might be looking at it, but really to also set this sort of context and scene to carry on all of these other little studies on top of it. So that helps #1 funding #2 methods. So I've split these into sort of four sections. The adaptation methods which I will describe to you briefly, who to include in the mixed methods pilot study, how and where to recruit, and what outcome measures to use. These were all influenced by that original qualitative study. So when we go to the adaptation, how do we adapt a programme developed in Uganda? That's me visiting

Uganda and visiting one of the groups on grass mats under a tree that went on for about 5 hours because people sort of dropped in and out as they could get transport. How? Do we adapt that? To an NHS setting here in East London, where we've got loads of different languages spoken, we've got parents who also overwhelmed by medical appointments. They might not have a day to get to a group and sort of relax and stay. For a while. In the NHS, which has got constrain. Yeah. How did we do that? So we used it. We used a framework called the ADAPT framework, which provides quite flexible suggestions as to how to adapt interventions for new contexts. And one of the points it makes within the article that says qualitative research can be beneficial in deepening the understanding of a new context, and that's that's generally what I've been saying, is that the qualitative study really deepen the understanding of the context of East London and the needs of the parents and healthcare professionals working there. And the ADAPT guidance says that we can do something called context mapping which is thinking about mapping the different contexts. So we've got Uganda there. That's one of the groups. Then we've got Norm and Tower Hamlets where we're adapting it to and really focusing potentially more on similarities rather than. Differences, and I think what's very useful about context mapping is the stories, because stories can be quite relatable no matter what country you're in, and. And so the stories from the qualitative work. From east London, we found feelings of isolation. It was often mothers being the primary caregiver. There was difficulty sharing mental health struggles, but sharing stories helps parents. To feel less learned. And all of those things could be related to parents in Uganda too. And I think that also. Shows the power of. Of storytelling, because they were telling me stories very similar to similar to that. There were obviously differences too, and I've spoken about those differences and resources and differences in cultural ideas about disability. But that really helped us with the adaptation, really mapping out the two contexts using stories. That was the adaptation, who to include in the sort of mixed method study. And originally we were going to use, we were going to use. Our sort of recruitment. Criteria to be just children with cerebral palsy, but actually these quotes are not qualitative. Studies showed us that we needed to broaden our criteria. So this. Parent in the first. It is when I saw some of your slides about communication, mobility, how to feed all of these apply to me, but my child doesn't have cerebral palsy. And this healthcare professional speaks about her complex needs workload. Only maybe 5% of our caseload is cerebral palsy, so it really helped us to know we need to pull the criteria not mentioned here is about the age group and actually in the qualitative study, we found that. Parents really wanted that support just after diagnosis or a few years after, and that was a really key transition period. Also, as they went into primary school and so that helped us to know, to target what age group as well in the mixed method study. So we've gone for under five years old children under 5. The qualitative study also gave us ideas about how and where to recruit for the larger study. These were all ideas provided by parents and healthcare professionals who were who were participants, and we've actually used quite a lot of these in recruiting for our current study. Ideas about recruitment? And then also, what outcome measures to focus on? And so participants in the qualitative study. Felt that the following outcomes might be expected improvement in parent care and mental health. Improved peer support and improved knowledge of services and their child's condition. No way. Did they really say they thought. Would. Improved dramatically their child's quality of life, but interestingly, all previous studies were studying that, and so it helped us to know

that maybe we need to move away from the child's quality of life. That's quite far away. That's quite distilled to what we're doing and can be influenced by so many different things and maybe we need to be focusing on actually what we're doing, which is. Empowering caregivers trying to improve their well-being. And their knowledge of service. That's so then we were able to also working with literature come up with outcome measures that we're using for our mixed method study, which are not necessarily focused on the child health, but more focused on the parent empowerment, their sort of health literacy and their activation in approaching healthcare services and also with the. Or mental well-being. Right. So. We've done methods, we've done funding. Now we're doing key decisions around implementation. So in a. Qualitative study, we were able to explore all of these sorts of aspects of implementation, whether to do it online, what facilitators to use, how long the group should be, whether we should include home visits, what we should do about other children, should they attend the groups, how do we account for differences in languages, and how do we account? Or different children and with a different sort of severities of diagnosis. I've got a few quotes here which just show how we were able to use some of the qualitative work to inform our decisions. The facilitators, it was unanimously agreed. That we should have. A parent facilitator with lived experience. As well as a. Healthcare professional and there is sort of courts have just highlighted, they put people's minds at ease. And. Might be better received by parents if it's someone they can relate to. Power of stories. Again, the timing of the programme. There were so many different variations with this. So when to actually introduce the programme to a parent. Some parents said it takes a long time to digest it to accept, so maybe if they're just aware of it, they can join whenever they like. Another parent said. We would shock. For Mr yeah. So maybe a year later, another parent said if you presented to me in. The first years I probably. Wouldn't go. So it's about. We've tried to make it as flexible as possible for any children under the age of five. They can sort of attend when they're ready and there's no pushing. And we have really found that in our in our current study. And then the online optionality? Some parents felt like it would be very impersonal if you're online, but others realise. It would be. More flexible and allow parents to attend, but you don't want to sort of lose that rapport that you get when you're online. If we think about the manual now, so we've talked about implementation and we go for the manual. So we were able to get detailed recommendations from participants for each different module of the manual, as well as suggestions for future modules. And so through using all of that qualitative data. We brought in. That to workshops with parents and with healthcare professionals, and we're able to adapt them. And all together, but it really was done first with all of that qualitative work, we kept much of the same actually in our Encompass project but adapting different parts of each module. We've included the module and going to school because that came up. Quite a lot in the qualitative study about parents you can support in going into school. Thinking about education, health and care plans as well. And I've added. 1/5 section about additional funding because. As much as I thought I was. Very. Thorough in my first funding application, there were different gaps and and so able to get further funding to fund the parent facilitator and extra tourist equipment and refreshments for the groups. And when I was developing those extra funding applications, I went back to the qualitative study and brought our quotes and brought up some of the themes that were developed then. And I do actually think that's why as well. That's why funding has come through again and again, because we do have

evidence from parents and and those stories and the quotes can be very powerful too. Yeah. Currently we do have a adapted manual and this is actually one of our groups, looks a little bit chaotic there, but we've got children on laps around around the mat, not so much on grass mats outside of tree, but we are busy piloting the groups and we've got two groups growing one in Newham and one in Tower Hamlets. And we've trained up. Parents in the community to deliver it alongside an artificial therapist in one borough and a physiotherapist in another. That all of those tiny sort of steps to get to this phase and all of the planning really was influenced by that original study. And if we keep moving on past this current. Mix with the study that I'm doing. There was a huge amount of data around older children as well, and that transition time into secondary school and how there really is even less support. At that time. And there's future work to be done there, potentially to develop new modules or even a new programme. But there are loads of quotes from that first qualitative study around how important transitioning is and it this healthcare professional says it's not really relevant when you're not in that phase, you're not really going to listen to it and actually maybe. We need to think about. A new phase or a new module and actually we are thinking about applying for funding for this, using the results from the original study. And I think just to think about the power of stories of kind of alluded to that throughout the talk. But stories from the qualitative study, as I've said, have influenced the mixed method study. But stories from the parents as well in the parent partners group, the PPI group that I spoke about, they also supported the development of the manual and they I spoke to a few of them before I came back came this evening and they said they see their stories through the manual too. And they see. How their lived experiences reflected in those? Stories from the parent facilitators within the group are extremely powerful for the parents who are attending the group. They often have children who are sort of teenage or bit older, and they have walked a long journey and that is really the power of the group in terms of. Storytelling and peer support. And then finally, stories between the participants as well. It's a very important part of peer support. We had one module where the content sort of went out the window as it became very much a sharing session, but actually that is the the power of these groups is providing that peer support and that problem solving together. And it's sometimes being flexible to allow for this to come through more than sort of more of the teaching. So I was trying to think how to summarise. This and. And I think I just thought about how much data there was from that first, fairly small qualitative study and how this has informed every aspect. From the planning to the doing to future planning as well of their current mixed method study and how it's worth considering it at the start of a larger project, we've got so many different options to build up from here now and there's so much future work to be done, but it really did have a really good solid base as well. And stories are powerful to form, sort of. That local contextual understanding of the group and of the population, and that allows us to build programmes on top of. That. I think this one is a picture of one of the groups we used. To run in South Africa as well. And thank you. I have a little screenshot of our website there which we do try to keep updated, but I hope that's been somehow helpful and I'd love to hear what people think and if they think there's sort of use and qualitative work in their current ideas and how that might influence what you're doing. Yeah.